

## Hawai'i's Alzheimer's Disease Initiative: Reflections on and Future Directions for Building a Dementia-Capable Health System

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### Introduction

Dementia, an umbrella term for Alzheimer's disease and related dementias, presents a challenge to health and long-term care systems. In Hawai'i, there are an estimated 29,000 individuals with Alzheimer's disease, and this number will rise to 35,000 by 2025 with a significant proportion of the population undiagnosed (60%-80%).<sup>1</sup> Dementia is characterized by a gradual loss of brain function that becomes severe enough to affect daily life and signals the critical need for early detection and better support for patients and families. However, individuals rarely receive cognitive testing in primary care settings, which is recommended best practice. Often families do not bring memory concerns to the attention of providers as they attribute the memory loss to normal aging. Yet early diagnosis is key to early interventions and planning for care and supportive service needs.<sup>1</sup> As the disease progresses, families require coordinated long-term services and supports (LTSS) and advance care planning, but they often encounter a fragmented health and long-term care system in Hawai'i as in the rest of the United States.<sup>2,3</sup>

Federal directives push states to be "dementia capable" by addressing the needs of people with dementia and their caregivers through a person-centered and coordinated system of care. Specifically, dementia capability is defined as having professionals skilled in identifying individuals with possible dementia, working effectively with individuals and caregivers, understanding service needs, and referring to agencies able to provide such services.<sup>4</sup> In 2013, the Hawai'i's State Executive Office on Aging (EOA) published its State Plan on Alzheimer's Disease and Related Dementias and identified several critical goals and strategies toward becoming dementia capable, however, the EOA lacked the resources for implementation.<sup>5</sup>

Federal Administration for Community Living (ACL) funding given to the University of Hawai'i Center on Aging from 2015-2019 funded the Hawai'i Alzheimer's Disease Initiative (HADI) and provided critical resources to improve dementia capability in Hawai'i. HADI's main goal was to progress toward dementia

capability through several objectives: (1) promote early detection of dementia, (2) provide improved coordinated services for people with dementia and their families, and (3) support dementia caregivers by providing needed skills and education. The purpose of this column is to describe HADI's efforts and accomplishments, highlight remaining gaps, and discuss next steps in fully realizing dementia capability statewide.

### 1. Promoting Dementia Capability and Early Detection

HADI's first key approach to promoting dementia capability in the state was through training Hawai'i's health care providers, including primary care providers, other allied health professionals, paraprofessionals, and family caregivers statewide. The core concepts covered by the training included: (1) basic dementia capability, specifically distinctions between normal aging and dementia, treatments, and communication strategies; (2) the use of the AD8 Dementia Screening Interview (AD8) and Mini-Cog screening tools<sup>6,7</sup> to promote early detection; and (3) special topics including non-pharmacological strategies to manage behavioral challenges and end-of-life care. To accomplish this, HADI coordinated in-person and virtual trainings in partnership with the John A. Burns School of Medicine, Department of Geriatric Medicine, Geriatric Workforce Enhancement Program, and Kōkua Mau, a Hawai'i non-profit organization which focuses on advance care planning, hospice, and palliative care.

To promote early detection, HADI trained health care providers on the use of the Mini-Cog and AD8 as reliable best practice screening tools.<sup>6,7</sup> The Mini-Cog is a brief cognitive screen that includes a clock drawing and three-word recall. The AD8 is an eight-question screening tool that can be administered over the phone or in person to the person with dementia or caregiver. During these trainings, professionals and paraprofessionals practiced administering these tools and HADI recommended protocols to integrate these tools into daily work. In total, 9166 individuals attended 206 trainings and public presentations. The

trainings were endorsed by non-profit organizations and health system leadership. While we did not specifically evaluate the degree to which the knowledge gained continues to be applied in practice and the sustainability of any system changes, evaluations administered post-training indicated that most trainees (86%) believed that the information was useful and will be applied in their professional practice.

## **2. Coordinated Care for Persons with Dementia**

In addition to training, HADI created new models of care coordination to help families better navigate the health and long-term care system, including: (1) an interdisciplinary “memory clinic” model, and (2) memory care navigation.

### **Memory Clinic**

The first memory clinic in the state was created in 2010 at Kōkua Kalihi Valley Comprehensive Family Services, a federally qualified health center (FQHC) based on the Patient-Centered Medical Home model.<sup>8</sup> HADI replicated this model in 3 additional FQHCs at Kalihi-Palama Health Center, West Hawai‘i Community Health Center, and Moloka‘i Community Health Center. To obtain buy-in from the FQHCs, HADI partnered with the Hawai‘i Primary Care Association to present the memory clinic model during regular meetings of its FQHC membership as well as met individually with FQHC leadership. The goal of the memory clinic is to offer a comprehensive geriatric assessment, cognitive testing, behavioral health services, social services, advance care planning, and brain health and fitness services. The memory clinic is held once a month and persons with dementia and their caregivers are seen by an interdisciplinary team of providers (primary care provider, behavioral health specialist, social worker, care coordinator, and nutritionist) in a group visit setting. The model is financially sustainable because these providers bill the patient’s health insurance for reimbursement of services. There is a huddle at the beginning and end of the memory clinic to discuss cases and ensure coordinated care.

Three newly established memory clinics served 141 patients and family caregivers over the course of the HADI grant. The following outcomes have been reported: patients’ health and social issues that were identified during the clinic (including caregiver education and improved health literacy) were addressed in 94% of cases and referrals to LTSS were accepted in 72% of cases. The 3 FQHCs provided care to medically underserved patients, but to serve truly the state needs, the memory clinic model requires expansion to other areas and other types of health and long-term care organizations across the islands. Additional planning and resources will be needed for expansion. The most significant challenge HADI faced in creating the 3 new memory clinics was sustainability, as both rurally located memory clinics, in Kona and Moloka‘i, experienced staff turnover and required re-training.

## **Memory Care Navigation**

HADI created a memory care navigator (MCN) model, based on collaboration with expert advisors from the Barclay Group, LLC, nationally-recognized consultants in the field. MCNs are trained to work with people with dementia and their caregivers using a culturally-appropriate approach, educating families about dementia and connecting them to LTSS in the community. The initial training in 2016 was conducted with 117 nurses, social workers, and volunteers from non-profit organizations, health plans, and government agencies. Committed champions to the MCN model include a statewide friendly visitor program (Project Dana), the Hawai‘i State Public Health Nurses (PHNs), and case management staff at Lanakila Multipurpose Senior Center (LMPSC) who continue to provide memory care navigation. To date, 147 clients received memory care navigation (average 3.6 visits per client). Navigators reported that the identified health and social challenges noted by the family caregivers and people with memory loss were addressed in 49% of cases, and clients and family caregivers utilized LTSS services in 68% of cases. The impact of this MCN model was driven by strong non-profit and health care organization leadership, which prioritized the need to better assist their clients with memory loss and reinforced the implementation of the memory care navigation model.

## **3. Support for Caregivers**

In 2017, about 157,000 family caregivers in Hawai‘i provided an estimated 131 million hours of care to an adult with limitations in daily activities at an estimated economic value of \$2.1 billion.<sup>9</sup> Caregivers were an important target of HADI’s efforts, recognizing the significant role that informal family caregivers play in dementia care. Often, the most challenging tasks in caring for individuals with dementia involve managing challenging behaviors, including wandering and agitation, which can occur during advanced stages.

### **Savvy Caregiver**

To improve the ability of caregivers to address behavioral challenges, HADI adopted the evidence-based Savvy Caregiver program. The 6-week, in-person, group psychoeducational program provides dementia caregivers with the knowledge, skills, and attitudes needed to carry out their role as a caregiver. HADI trained 93 caregivers over 5 sessions at different locations on ‘Oahu and at the 6-week follow-up, findings indicated that participants had an improved caregiver reaction to caregiver recipient behavior ( $P < .01$ ), and decreased depression ( $P < .01$ ). Further reach to more dementia caregivers was limited by availability and capacity of the 2 trained facilitators, who taught dementia caregivers practical skills as well as led them in discussion and problem-solving activities. A train-the-trainer approach to expand the availability of this program statewide is needed.

## Positive Approaches to Care

Additional caregiver education was provided through Positive Approach to Care (PAC) trainings, a nationally recognized training developed by an occupational therapist and delivered via in-person, group sessions by a local certified trainer.<sup>10</sup> The content focused on making positive connections, helping caregivers see more than just loss, addressing challenging behaviors, assisting with feeding and dining tasks, and preparing for the end of life. Both Savvy Caregiver and PAC focus on providing family caregivers with the practical knowledge needed to keep their loved one with dementia at home and maintain their quality of life.

## Impact

Over the 4 years of federal funding and implementation, HADI successfully included a range of partners in the aging network, including the Executive Office on Aging, University of Hawai‘i Department of Geriatric Medicine, Alzheimer’s Association Aloha Chapter, Hawai‘i Department of Health Developmental Disabilities Division and Public Health Nursing branch, Project Dana, Kōkua Mau, and Catholic Charities. These partnerships were critical in providing knowledge and skills to health care professionals, state agencies, and community organizations on the concept of dementia capability and the vision to create a dementia-capable Hawai‘i.

These partnerships were also important in building and implementing new models of care, including the memory clinic and MCN. In order to build interest and collaboration in interdisciplinary efforts, understanding the motivations of different providers was important. In particular, FQHCs are motivated in primary care and behavioral health integration as many are recipients of Substance Abuse and Mental Health Services Administration (SAMHSA) funding which advocates for integrated care models.<sup>11</sup> Buy-in from leadership and management at each FQHC, with support from Hawai‘i Primary Care Association, was also a critical component. These leaders championed HADI’s work and were key in ensuring that staff were dementia capable and both the memory clinic and memory care navigation models were sustained. Connections and collaborations with non-profit service providers were also important to reaching and recruiting family caregivers. These partners were supportive and embraced evidence-based and best practice caregiver support programs, but lacked the resources and staffing to implement these programs on their own.

## Remaining Gaps

HADI has made significant strides in strengthening the health care workforce and improving supports and services for families with dementia. But there are remaining gaps. Further expansion and scaling of the memory clinic and MCN models are needed, as well as connections to the larger state agencies and hospital systems. On an individual level, cultural tailoring of messages related to the early detection of dementia and risk reduction is needed to dispel myths and stigma around mental illness and caregiving within Asian American and Pacific Islander populations. Although the MCN training included discussion of diverse populations, and Savvy Caregiver was culturally adapted to Hawai‘i’s diverse communities, additional work is needed. In particular, lessons learned from working with Pacific Islander populations indicate that messages about the importance of early detection are difficult to communicate because regardless of diagnosis or stage of the disease, the family tend to consider only informal sources of care rather than formal care and are reluctant to reach out for help.<sup>12,13</sup> An additional area of focus includes people with dementia who are living alone, a challenging population to reach and serve. Partnerships with community service providers, including community health workers, who are trusted by and can reach this population are needed. Finally, people with dementia need to engage in end-of-life and long-term-care planning early, while they retain the capacity to make decisions.

## Future Steps

Efforts to strengthen the systems of care for people with dementia and their families are continuing (See Table 1). Hawai‘i is fortunate to have received additional federal ACL funding to strengthen dementia care. In particular, the Executive Office on Aging is focusing on ensuring dementia capability among state agencies that are part of the No Wrong Door network.<sup>14</sup> State agencies are being trained in dementia capability, so that when an individual with memory loss or dementia comes through their agency “door,” staff are knowledgeable about the basics of dementia and available services. Staff will then make appropriate referrals to community-based memory care resources. In addition, this grant will address silos between the health and long-term care systems by streamlining care transitions among persons with dementia from hospital to home. Additional federal funding from ACL was also provided to Catholic Charities, which will provide additional outreach to culturally diverse faith-based communities and specifically target individuals living alone with dementia. Commitment to these issues continue to be strong, guided by an Alzheimer’s Disease and Related Dementias (ADRD) state plan, which is in the process of being updated. Through these grants and planning efforts, Hawai‘i is responding to its rapidly growing older population and building the services and supports critically needed for families who have a loved one with dementia.

Table 1. HADI Goals, Activities, Gaps, and Next Steps			
Goals	Activities	Gaps	Next Steps
<ul style="list-style-type: none"> <li>Promote early detection</li> <li>Coordinated dementia care services</li> <li>Support dementia caregivers</li> </ul>	<ul style="list-style-type: none"> <li>Training to professionals and family caregivers</li> <li>Memory clinic</li> <li>Memory care navigation</li> <li>Savvy Caregiver</li> <li>Positive Approach to Care training</li> </ul>	<ul style="list-style-type: none"> <li>Scaling of models statewide</li> <li>Cultural tailoring of programs and services</li> <li>Reaching those who live alone with dementia</li> <li>Promote end-of-life planning</li> </ul>	<ul style="list-style-type: none"> <li>Strengthen further connections between state agencies and community LTSS</li> <li>Address silos between health and long-term care systems</li> <li>Update Hawai'i ADRD state plan</li> </ul>

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## References

- Alzheimer's Association. Alzheimer's Disease Facts and Figures. *Alzheimers Dement*. 2019;15(3): 321-387.
- Edwards, BC, Sen, AP. High demand and fragmentation: The current state of long-term services and supports in America. *Generations*. 2019;41(1):18-22.
- Long-term Care Reform Options in Hawaii: Final Report. [www.publicpolicycenter.hawaii.edu. http://www.publicpolicycenter.hawaii.edu/projects-programs/\\_long-term-care/RTI\\_Options\\_Report-FINAL.pdf](http://www.publicpolicycenter.hawaii.edu/projects-programs/_long-term-care/RTI_Options_Report-FINAL.pdf). Published March 2011. Accessed May 18, 2020.
- Tilly J, Wiener J, Gould E, O'Keeffe J. *Making the long-term services and supports system work for people with dementia and their caregivers*. Washington, DC: U.S Administration on Aging; 2011.
- Hawaii 2025: State Plan on Alzheimer's Disease and Related Dementias. [www.hawaiidrc.org. https://www.hawaiidrc.org/site/439/reports\\_publications.aspx](https://www.hawaiidrc.org/site/439/reports_publications.aspx). Published December 2013. Accessed April 21, 2020.
- Borson S, Scanlan JM, Chen PJ et al. The Mini-Cog as a screen for dementia: Validation in a population-based sample. *J Am Geriatr Soc*. 2003;51(10):1451-1454.
- Galvin JE, Roe CM, Xiong C, Morris JC. Validity and reliability of the AD8 informant interview in dementia. *Neurology*. 2006;67(11):1942-1948.
- Fernandes R, Hla MM, Compton M, Chang C, Masaki K, Hosokawa MC. Memory clinic model for underserved populations in a patient-centered medical home. *Ann Gerontol Geriatr Res*. 2014;1(4):1017.
- Valuing the Invaluable: 2019 Report*. Washington, DC: AARP Public Policy Institute; 2019.
- Murphy J. Positive approaches to care: A new look at dementia education. *Prim Health Care*. 2017; 27(1): 29-33.
- Scharf DM, Eberhart NK, Hackbarth NS, et al. Evaluation of the SAMHSA primary and behavioral health care integration (PBHCI) grant program: Final report. *Rand Health Q*. 2014;4(3):6.
- Chow JC, Auh EY, Scharlach AE, Lehning AJ, Goldstein C. Types and sources of support received by family caregivers of older adults from diverse racial and ethnic groups. *J Ethn Cult Divers Soc Work*. 2010;19(3):175-194.
- The Emerging Needs of Asian American and Pacific Islander Older Adults: What We Know and What We Have Learned*. Seattle, WA: National Asian Pacific Center on Aging; 2017.
- Key Elements of a NWD System of Access to LTSS for All Populations and Payers. <https://nwd.acl.gov>. <https://nwd.acl.gov/pdf/NWD-National-Elements.pdf>. Accessed May 1, 2020.